

Minutes
Traumatic Brain Injury Advisory Council
Dorothea Dix Campus
Kirby Building Room 297
Raleigh, North Carolina
June 8, 2004

Members Present

Sandra Farmer	Martins B. Foil	David Forsythe
Lynn Freeman	Betty Gardner	Bob Gauldin
Tonia Harrison	Al Hart	Stephen Hooper
David Mills	Charles Monnett III	Brenda Motsinger
Ila Nofzinger	Patrick O'Brien	Jo Perkins
Sharon Rhyne	Jamessa Selleck	Elsie Siebelink
Jack St. Clair		

Members Absent

David Atkinson	Spencer Clark	David Good
Debbie Leonhardt	Layla Mabe	Holly Riddle
Carol Robertson	Robert Wm. Seligson	Steven Strobel
Dennis A. Turner		

Others Present

Peggy Balak	Beth Callahan	Senator John Kerr
Bud Nofzinger	Grey Powell	Ben Staples
Tamara Toner	Judge Kristin Ruth	

Chairperson, Sharon Rhyne, called the meeting to order at 10:10 AM. She opened the meeting with a brief introduction of herself and greeted the Council members and guests. She recognized the need for the group, per the legislation, and the significance of the issues before the Council. She then introduced Honorable Judge Kristin Ruth for the swearing in of the members. Bibles were passed out and Judge Ruth performed the official swearing in of the Council members.

Chairperson Rhyne asked that the members of the Council introduce themselves and identify one or two accomplishments they would like to see the Council accomplish:

Sharon Rhyne – Ms. Rhyne is the hospital and trauma specialist for the North Carolina Office of Emergency Medical Services. As such, a variety of concerns specific to brain injury (injury prevention, prehospital care, acute hospital care, rehabilitation, etc.) fall under her purview. She oversees the state trauma registry and has worked in the past with the NC Brain Injury Association, Project Access initiatives, and the work group that led to the “North Carolina Action Plan for Persons with Traumatic Brain Injury”. She would like to see the Council pick at least one or two specific goals and make sure they are accomplished, rather than spending time on a variety of initiatives and accomplishing little to benefit brain injured patients and their families.

Jamissa Sellek -- Ms. Sellek is from the western part of the state and has two family members with brain injury (son and husband). She would like to see increased access to the services available and would like to have the definition of brain injury related to services include acquired brain injury, not just traumatic.

Elsie Siebelink, RN -- Ms. Siebelink recently retired from the ECU at Greenville Brain Injury Rehabilitation program. She noted that once the family leaves the acute setting of the health care facility, living with a person with brain injury and dealing with the service network can be very confusing. She noted that the families are often at a loss to effectively negotiate the service delivery maze.

Steve Hooper, Ph.D.-- Dr. Hooper is a pediatric neuropsychologist with the Department of Psychiatry at UNC and is interested in life span issues. He is the Assistant Director for the Clinical Center for Development and Learning (CDL). He is interested in system of care issues as

it relates to the region. He is also interested in education (what the general population knows about brain injury and increasing their understanding of the implications of the injury).

David Mills – Mr. Mills is from the Department of Public Instruction, Areas of Exceptional Children, educated as a Speech and Language Pathologist and is currently working with 115 school districts and 96 charter schools to oversee services for persons with traumatic brain injury. He also oversees the TBI Registry for the Department of Public Instruction for school psychologists. Mr. Mills noted his interest in increasing support in the schools, using teams of care within the districts, and prevention.

Jo Perkins – Ms. Perkins works with the Division of Vocational Rehabilitation. She noted that she was in an automobile accident and has experienced memory loss. She indicated interest in working with the Division related to the needs of people with brain injury, improving communication to alleviate miscommunications about the availability of benefits, and focus on issues that we could do something about. Ms. Perkins indicated that employment and housing are very important to persons with a brain injury. She feels that equity and collaboration among the various state agencies involved is critical to being successful in providing services.

Ila Nofzinger – Ms. Nofzinger is the parent of a 49 year old survivor. Her daughter experienced an acquired brain injury and has been challenged to receive the desired services. She would like to see the definition changed to exclude the 22 year old age limit. She noted that her daughter responded well to treatment. However, due to service limitations, she was forced to choose between support or therapy. Her daughter is now in a nursing home but she feels that her life would have been much improved if services could have been sustained.

Bob Gauldin – Mr. Gauldin is a former teacher and coach that survived a fall 12 years ago resulting in brain injury. He is interested in resource access for people with a brain injury. He noted that most people with a new injury do not know the questions to ask in order to be appropriately directed. He suggested a mentor program that would provide direct assistance and support. Mr. Gauldin indicated that there are a variety of services available to survivors but they often do not know how to access them.

Al Hart – Mr. Hart is a Nortel Engineer who experienced an aneurysm. He thanked Council member Dr. O'Brien for making him work so hard in association with his treatment at WakeMed. Mr. Hart recognized that the information needs of the patient rest with the discharge planners and social workers. He feels that there should be a consistent message from these groups in order to assist patients. He noted that there should be increased education and publicity about brain injury and the impact it can have. He noted that the discharge planner has the responsibility for enlightening the family but, at the time, the caregiver is not hearing the information and the survivor is not able to retain the information. He noted, "You are good enough to be released, but you don't have an idea of what to do." Mr. Hart indicated that corporations would like to assist in the education of the public through sponsorships. He feels that education is necessary to know what resources are available.

Betty Gardner, RN – Ms. Gardner is with the Department of Facility Services. She noted that she had hospital experiences as a nurse having first worked in a neurology unit. She recognizes the need for increased advocacy with improved quality and systems of care in place. She indicated that there should be systems to facilitate the maximization of one's ability.

Jack St. Claire – Mr. St. Claire works with a four county Area Program and has two family members involved with brain injury. He is a supported employment vendor and is also involved with ReNu Life. His son had a diving accident and was treated at UNC. Mr. St. Claire questioned where the State is regarding the development of a TBI WAIVER. He noted that this group could be a way to get issues resolved and link together extended rehabilitation as well as housing & support. Honorable mention made for Sen. Kerr and his support for this group.

Brenda Motsinger – Ms. Motsinger is with the Department of Public Health, Injury Prevention. She is interested in looking at the underlying causes from a prevention perspective. Her area of specialization is violence prevention.

David Forsythe – Mr. Forsythe is a provider with Person County Group Homes, currently serving about 90 people and 10 with brain injury. He noted that individualized services plans are developed but that services are not available within the community to support the needs of the

clients. He feels that a new definition needs to be established as to what is allowable. His focus is that individual services be developed specific to ones needs; however our system does not allow for individual specifically designed services. The government has resources with certain definitions that are defined to be restrictive. Unfortunately, they often exclude those that need the service. He hopes that the Council can focus on the fact that there is no standardization array of services for those with brain injury, what it means and what the needs are. He feels that a waiver might help.

Lynn Freeman – Ms. Freeman is a State Employee and mother of a survivor. She noted that her son is a rising senior at ECU, experienced a significant injury in the past and now has severe depression. The depression is considered secondary to the brain injury. She noted that though her son is now six years out from his injury, the entire family has been impacted.

Tonia Harrison – Ms. Harrison is from Goldsboro and is a survivor of an automobile accident resulting in a brain injury. She had graduated from college as an x-ray technician two weeks prior to her injury. Her parents opened ReNu Life. She has experienced Early Intervention/Community Support but has had difficulty working due to having short-term memory loss. She would like to see society understand brain injury; recognize that it does not mean “brain dead”. Ms. Harrison noted that she lost a number of friends related to her injury. She acknowledged abandonment following her injury, noting that people are afraid of differences.

Martin Foil – Mr. Foil has a 19 year old son with a brain injury and has been very active in the brain injury community. He is the past Chairperson of the BIANC, the Brain Injury Association of America, and the International Brain Injury Association. Through the years, he has been active in fundraising. His interests are prevention, cure, and improving the quality of life. He is currently building a not-for-profit home that has not yet been approved by the state. He wants to be able to provide everything on a daily basis that people with brain injury need, as well as provide outpatient supports. He recognizes that money drives everything (money & influence), and that there is a way to accomplish what we want to do, we just must be creative. He feels that we need to tie TBI into areas that are appropriate for funding such as speeding tickets and other fines. He noted the need for a trust fund, as in some other states. Mr. Foil noted that the trust fund could be related to motor vehicle crashes since they are the most common cause for significant brain injury. He hoped that the Council could make a difference.

Chuck Monnett III – Mr. Monnett is an attorney in Charlotte and represents hundreds of clients with brain injury. He noted that an additional issue related to the injury is the disintegration of the family. He suggested that family units need support and would like to see us recognize those individuals with mild and moderate brain injury rather than traumatic only.

Sandra Farmer – Ms. Farmer is the current President of the Brain Injury Association of NC. She hoped the Council could assist in meeting goals that we can achieve and have an impact for persons with brain injury in NC. She noted that there are 18 states with trust funds currently with varying degrees of success.

Patrick O’Brien, MD – Dr. O’Brien is with WakeMed in Raleigh. He noted that he has issues with the distinction between mild, moderate, and severe since all brain injuries are severe. Severe disability results from the injury.

Chairperson Rhyne thanked everyone for their participation and noted how important it is that we work together for the common good of persons with brain injury.

Beth Callahan was called on to charge the group. She began by passing out notebooks with background information. She reported the history of brain injury legislation in North Carolina including how definitions were placed within the legislative structure for developmental disability in 1987. She indicated that with managed care came a number of problems for persons with brain injury including earlier discharges. The Traumatic Brain Injury Act of 1996 led NC to be one of the first states to seek grant funding (Project Access). She noted that there was a CAP waiver developed and it adheres to the federal guidelines. Money was made available to the state to improve service delivery.

Mr. Foil suggested that there might be benefit from the development of a trust fund to fund services for persons with brain injury. There are other states that have this model. However, it

was also noted that there could be problems with this model and it may deserve further exploration.

Comments were fielded from the members of the Council related to funding and assessment of the need:

Ms. Perkins noted that a recent grassroots effort had been made at the federal level to continue funding related to Technical Assistance. There was also discussion about capturing the number of persons that have brain injury in NC and the difficulties with securing an accurate count.

Mr. St. Clair and Mr. Foil queried the continued availability of state funds in the Developmental Disabilities budget. Both asked if the future dollars for brain injury would remain in the Developmental Disabilities budget. Ms. Motsinger noted her experience related to funding for projects and how it can be initiated with non-recurring funds, year after year, and eventually become permanent. However, without a reliable way to measure the number of people involved, funding is difficult to obtain. Mr. Foil suggested that we need a statewide needs assessment, including military bases. Discussion followed about the potential to secure grants, however the exact number of people who need services is not currently identifiable.

It was noted that the Trauma Registry, which captures information about substantial injuries, does not currently break out head injury as a specific entity. Issues with using the existing Trauma Registry to capture brain injury incidence figures were identified. For example, the Trauma Registry is a sample and not representative of the exact number because only the eleven trauma centers and a few additional hospitals are involved. There was discussion related to a registry versus surveillance and the Council was referred to the supporting documentation in their notebooks concerning how other states have addressed this point. Obstacles exist related to HIPPA which prevents healthcare providers from releasing the names of patients and their families to agencies who could provide valuable support services.

There was the distinction made between the incidence of brain injury in the state and service needs. There is the potential to seek a one year demonstration grant from HRSA for \$100,000 related to needs assessment. It was suggested that the available information from the Research Triangle Institute be reviewed and that Research Triangle Institute (RTI) and CDL be considered if additional data reports are required.

MOTION: A motion was made by Mr. Foil, and seconded by Mr. Mills to authorize Ms. Callahan to pursue, with the Division of Mental Health/Developmental Disabilities/Substance Abuse, moving the Statewide Action Plan for Persons with Traumatic Brain Injury off of DRAFT status when a majority of positive votes on the acceptability of the document are received from the TBI Council. After much discussion, the motion was amended to authorize Mr. Callahan to promote the draft as a working document with input from Council members by June 22, 2004 in order to develop a vote ready document. The motion passed unanimously.

Determination of Next Meeting Date and Adjournment

Prior to the next meeting members of the Council are to review the motion, minutes and the North Carolina Statewide Action Plan for Persons with Traumatic Brain Injury, the latter being found in their notebooks. It is recommended that they make comments on the Plan prior to June 22, 2004. These comments are to be directed to Beth Callahan and Ben Staples for compilation.

There was discussion regarding representation and absence of state agencies related to voting. All state agencies should send a delegate if the Council member is not able to attend. However, the delegate will not have voting authority.

Future meeting dates of September 28, 2004 and November 16, 2004 were selected, each meeting to begin at 10:00 AM and end at 2:00 PM. The specific locations in the Triangle area will be announced in the near future.

The meeting was adjourned at 1:55 PM.